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THE ROLE OF THE FAMILY

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SCHIZOPHRENIA TREATMENT PROGRAM
NATIONAL INSTITUTE OF MENTAL HEALTH
January 1986

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THE ROLE OF THE FAMILY

SCHIZOPHRENIA TREATMENT PROGRAM
NATIONAL INSTITUTE OF MENTAL HEALTH
January 1988

The Schizophrenia Treatment Program believes that the family can be a major positive force in the treatment of schizophrenia. The treatment approaches of this program all emphasize the important role of the family in working with their schizophrenic family member. Although the types of treatment differ, all emphasize that the family unit is a member of the treatment team. Both this initial psychoeducational workshop and the monthly family group meetings will provide information and suggestions other families have found useful to help with the problems of having a relative with schizophrenia. The key to the family's successful role in this program will be an understanding of schizophrenia. This understanding begins with this initial workshop, and will serve as the backbone of the monthly meetings as well.

**THE FAMILY CAN BE A MAJOR POSITIVE FORCE
IN THE TREATMENT OF SCHIZOPHRENIA**

WHAT TO EXPECT WITH SCHIZOPHRENIA?

Schizophrenia is an illness which requires treatment over a long period of time. During this time, a patient may have episodes when the symptoms get worse, something you may have observed in your family member if this is not his or her first experience with schizophrenia. For those having their first experience, however, it may be hard to accept that schizophrenia is not like a broken arm. A broken arm gets better, but is unlikely to return. Because you cannot "see" schizophrenia, it is hard to know how quickly progress is being made. There are three reasons why it is helpful to know that schizophrenia is a recurring illness: First, no one is to blame for a relapse as it is just as much a part of the illness as the symptoms; second, treatment can make a difference; and third, if a relapse does occur, noticing what kinds of things happen around that time may help to prevent or delay the next episode.

**DUE TO THE RECURRING NATURE OF SCHIZOPHRENIA,
TREATMENT IS REQUIRED OVER AN
EXTENDED PERIOD OF TIME**

**THE FAMILY PLAYS A CRUCIAL ROLE IN THE IDENTIFICATION
OF EARLY SIGNS OF RELAPSE**

**IT IS IMPORTANT THAT TREATMENT BE
INITIATED AS EARLY AS POSSIBLE**

THE MANY TYPES OF SYMPTOMS

Schizophrenia is sometimes hard to understand because it has so many different symptoms. It is usually not difficult to understand that disorganized thinking, hallucinations or delusions are a part of an illness. It may be harder to accept, however, that the social withdrawal, lack of drive or energy, loss of interest in goals even to the point of poor self-care, can be equally a part of schizophrenia. Sometimes, relatives may think the patient is just being lazy or spiteful. The patient may not even understand why he is behaving this way. Explanations of "I can't do something," or "I don't know," can lead to negative feelings in the family if they are not understood as being a part of the illness. Remembering the wide range of signs and symptoms can help in planning during the recovery process.

**RECOGNIZE THAT THE SYMPTOMS OF SCHIZOPHRENIA CAN
INCLUDE DISORGANIZED THINKING, HALLUCINATIONS,
DELUSIONS, AS WELL AS SOCIAL WITHDRAWAL, LACK OF ENERGY,
LOSS OF INTEREST IN ACTIVITIES**

THE EARLY IDENTIFICATION OF EARLY SIGNS OF RELAPSE

The family is most important in recognizing signs of relapse as early as possible. The family may be able to spot these early signs before either the patient or the clinician. For many patients there is enough time after an early warning to allow some action, like an increase in medication, to keep a full symptom relapse from happening. In our program, the treatment team will work with you to provide information on the *general* patterns these early signs may take. It will be just as important, however, for you to tell us information about the *specific* changes or cues that you may have noticed about your family member just before relapse. In meetings you and the patient had with members of the team during these early weeks following the hospitalization, you have been asked questions about how your family member felt just prior to seeking treatment for this current illness — questions like, "Did he lose interest in doing things?" We also asked about any specific feelings you may have noticed in him. The same questions were asked of the patient. During the coming months, the team will be helping you and the patient to watch for these signs and to become aware of other cues that can tell us that a relapse may be coming. For example, at each medication visit, the program nurse will be asking about both the general signs and also the specific cues that *you* and the patient described. We will also need your help in developing the list of specific cues as the treatment progresses. You will be given a telephone number to call to notify the team if you see a possible sign of relapse, or to ask questions.

**THE FAMILY PLAYS A CRUCIAL ROLE IN THE IDENTIFICATION
OF EARLY SIGNS OF RELAPSE**

THE ROLE OF STRESS MANAGEMENT IN SCHIZOPHRENIA

It is generally recognized that some forms of stress are particularly problematic for the recovering patient, although the exact role of specific stress in schizophrenia is not known. Stress may arise from both within and outside the family. At times the stressors can be anticipated (e.g., starting a new job); at other times, stressors are unexpected (e.g., an auto accident).

One of the major periods of stress, especially for young men, is in early adult life, a time when they are striving to get a good job, develop close relationships and establish their independence. This is the most common time for schizophrenia to develop in men. For women, a major period of stress may occur somewhat later during periods of childbirth and childrearing associated with a later time of onset of schizophrenia.

Some of the more common sources of stress which occur outside the family include coping with work or school, welfare and financial issues, relationships with friends, employers, etc. In addition to stressors external to the family, stresses can also arise within the family. Studies have shown that the environment in which a patient lives can help him/her if the patient is encouraged to *gradually* regain his former skills. Although it is impossible to avoid stress totally, family members are most helpful when they help one another to cope with difficulties in their lives and to attain realistic goals.

The treatment team will be helping you to recognize what stresses may be important to your family member during the recovery period and enlisting your help in finding ways to reduce them.

**IT IS IMPORTANT TO IDENTIFY AND REDUCE SOURCES OF STRESS
BOTH WITHIN AND OUTSIDE THE FAMILY**

NOTICING AND SUPPORTING SMALL STEPS IN RECOVERY

All patients who will be entering the treatment program will be recovering from an acute episode of schizophrenia. As in recovery from any other serious illness, it is important not to return too fast to the activities the person did before the illness. Because schizophrenia does not have physical signs like a broken arm with pain that can signal that the healing process is not complete, slow progress on the part of the patient is often misunderstood as a lack of trying. Because we know this is not so, it is important that the patient's small steps — like coming down to dinner, shaving, or even saying "hello" to someone in the kitchen — be noticed and appreciated. It is only through a continued accumulation of these *small* steps that full recovery will be possible.

**IT IS IMPORTANT THAT A PATIENT'S SMALL STEPS
IN RECOVERY BE NOTICED AND APPRECIATED**

THE IMPORTANCE OF KEEPING APPOINTMENTS

Because we know that the recovery from schizophrenia will require an extended treatment period, keeping all appointments for the full treatment program will be very important. It is not unusual for patients who begin to feel better or who are having some side effects with the medication to not want to keep their regular appointments. If this becomes a particular problem in your family, it should be discussed immediately with the treatment team.

**IT WILL BE VERY IMPORTANT TO KEEP ALL APPOINTMENTS
AS THEY ARE OPPORTUNITIES FOR EVALUATING THE SPECIFIC
TREATMENT PLAN FOR THE PATIENT**

Please do not hesitate to ask any questions you may have about schizophrenia. We are looking forward to your participation as a member of our treatment team. By our working together over the next two years, we hope to be able to provide the best possible treatment for schizophrenia.

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NOTICING AND SUPPORTING SMALL STEPS IN RECOVERY

**IT IS IMPORTANT THAT A PATIENT'S SMALL STEPS
IN RECOVERY BE NOTICED AND APPRECIATED**

SUMMARY

1. THE FAMILY CAN BE A MAJOR POSITIVE FORCE IN THE TREATMENT OF SCHIZOPHRENIA
2. IT IS IMPORTANT FOR THE FAMILY TO RECOGNIZE: THE RECURRING NATURE OF SCHIZOPHRENIA; THAT RELAPSE IS AS MUCH A PART OF SCHIZOPHRENIA AS THE SYMPTOMS; AND THAT TREATMENT CAN MAKE A DIFFERENCE
3. THE FAMILY PLAYS A CRUCIAL ROLE IN THE IDENTIFICATION OF EARLY SIGNS OF IMPENDING PATIENT RELAPSE
4. KEEPING ALL APPOINTMENTS FOR THE FULL TREATMENT PROGRAM WILL BE VERY IMPORTANT

